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Sex and the Mentally Retarded: Is Sterilization the Answer?

SUMMARY

The sexuality of the mentally handicapped concerns them, their parents, their family physicians and other health professionals. Parents need advice, and the well-informed family physician who has the family's trust is in a good position to give it. However, the physician must protect the rights and autonomy of the mentally handicapped patient concerning contraception, surgical sterilization and hysterectomy. Before recommending a method of contraception, the physician must identify any medical risks and be satisfied that the patient clearly understands risks and advantages. Sterilization as a method of contraception should never be considered unless the patient chooses it; involuntary sterilization can produce serious and significant psychological damage. The physician must give a detailed explanation to make sure the patient electing to be surgically sterilized understands the procedure and has fully consented without coercion. Hysterectomy should never be used as a method of sterilization. (Can Fam Physician 1983; 29:1474-1479).

SOMMAIRE

La sexualité des handicapés mentaux les concerne eux-mêmes, leurs parents, leurs médecins de famille et les autres professionnels de la santé. Les parents ont besoin de conseils, et le médecin de famille bien informé qui jouit de la confiance de la famille est bien placé pour les leur donner. Toutefois, le médecin doit protéger les droits et l'autonomie du patient mentalement handicapé concernant la contraception, la stérilisation chirurgicale et l'hystérectomie. Avant de recommander une méthode contraceptive, le médecin doit identifier tout risque médical et s'assurer que le patient en comprenne clairement les risques et les avantages. La stérilisation comme méthode contraceptive ne devrait jamais être considérée à moins que le patient ne la choisisse lui-même; la stérilisation involontaire peut engendrer des dommages psychologiques sérieux et considérables. Le médecin doit donner des explications détaillées afin de s'assurer que le patient choisissant la stérilisation chirurgicale comprenne bien la procédure et y ait consenti entièrement et sans contrainte. L'hystérectomie ne devrait jamais être pratiquée comme méthode de stérilisation.

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DURING NORMAL adolescence, both boys and girls are excited by their budding sexuality, afraid of experiencing sex, and fearful that they will prove inadequate if they display sexual behavior.[1] Mentally handicapped adolescents have the same feelings, although they may emerge later. The sex drive might be less urgent, but their sexuality and need for affection are no less vital.[2-4]

Heshusius observed handicapped people's attitudes and divided them into four main categories:

1. enjoyment of, desire for, or anticipation of sensual/sexual contact.
2. fear or anxiety about sexual contact.
3. a belief that intimate physical contact and sex should occur only after marriage.
4. ignorance about sexual relations.[5]

These needs have largely been ignored and society's attitude towards mentally handicapped people's sexuality has been inconsistent and generally negative.[6]

However, parents have long been concerned about their children's sexuality.[7-9] They are bewildered by con-

flicting advice from the professionals to whom they look for wisdom;[10] many have found the medical profession is not particularly helpful as they attempt to deal with anxieties about their handicapped adolescents' sexuality.[11] And yet, who is better equipped than the family physician to provide supportive counselling? The family doctor who has the family's trust and understands the sexuality of handicapped people can offer appropriate advice and support to parents attempting to deal with this vexatious issue.[12]

Fertility

Before the physician can logically approach the subjects of contraception and sterilization for mentally handicapped people, he must consider the issue of fertility. Are all retarded persons fertile and therefore candidates for contraception and sterilization? Smith and Berg found only 22 cases of females fully affected by Down's syndrome having children,[13] and "no fully affected male is known to have fathered a child".[14] Other authors[15, 16] suggest that numerous studies refute this. Although the fertility of women with Down's syndrome still seems to be in question, there is little dispute that males with Down's syndrome are sterile, making vasectomy an inappropriate choice for them.

For other mentally handicapped people, however, the question of fertility is very important. For most mildly intellectually handicapped people there appears to be no physiological impediments to reproduction and they are as interested in marriage and sex as anyone else.[17] However, fertility should never be assumed and family physicians would do well to "consider advising mentally retarded females to undergo a fertility test to determine their reproductive capacity. Infertility would preclude the need for contraceptives".[18]

Sex Education And Counselling

Johnson[19] defined three clear-cut philosophies about sex education, sexuality and counselling. The first holds that any sexual behavior not for procreation should be eliminated. Many believe this dictum applies particularly to mentally retarded adolescents.

The second philosophy is much more tolerant. "Believers in this philosophy often start out by more or less reluctantly tolerating the inevitable but often move on to more accepting positions . . .", accepting that the mentally retarded adolescent's sexuality ". . . is a reality to be dealt with rationally, knowledgeably and humanistically".[19]

The third philosophy suggests cultivating sexual gratification. Proponents of this philosophy believe that it is proper to teach sexually satisfying and individually appropriate techniques which may become one of the few sources of satisfaction for many mentally retarded individuals.

The last decade has seen many changes in community and health professionals' attitudes towards people with intellectual disabilities. Since the principle of "normalization"[20] has been accepted, there has been a shift from custodial and segregated institutionalization towards community integration. Such changes have given the mentally handicapped increased opportunities for forming relationships.[21]

Mental retardation ranges from very mild to very severe. If 95% of patients with intellectual disabilities are only mildly or moderately handicapped,[22] the need for sexual counselling is great. Most individuals with a mental handicap are born with the potential to develop 'normal' sex drives and do develop normal secondary sex characteristics.[3] They need sex education and sexual health care!

In counselling the retarded patient about birth control, the principal ethical issues are to insure that the risks and advantages of the various methods are clearly understood and that any medical risks are identified.[23] The family physician must articulate the pros and cons of each choice from the patient's perspective and must try to avoid imposing his own values on the patient, who may not have had the opportunity or the ability to learn about sex from books, parents, peers or schools.

The family physician may encounter difficulty with the parents of mentally retarded adolescents. Egyeda and Bentley[24] found that parents often underestimated their child's abilities and had difficulty in thinking of them as sexual beings. Johnson[25] states that most parents do not expect to teach social interactional skills, but this may be required of those with retarded adolescents. Parents may need to simplify, repeat, demonstrate and roleplay sex-related concepts.

Before examining and prescribing for the intellectually impaired adolescent, the issue of informed consent must be resolved; this will be discussed in association with surgical sterilization where it assumes even greater importance.

The Pelvic Examination

The pelvic examination must be approached with great sensitivity. "After an American female has been socialized into vigorous norms concerning society's expectations in the covering and privacy of specific areas of her body, especially her vagina, exposure of her pubic area becomes something that is extremely problematic for her".[26] If this is true of 'normal' females, one can imagine the effect of the procedure on the retarded. Great care must be taken to familiarize the patient with the examining room and with the instruments. Roleplaying may be appropriate. Audiovisual materials are available[27] and are often useful. At the time of examination the patient should be accompanied by a friend or by someone she trusts.

There are two questions about contraception: is it appropriate and what method should be used? A complete medical history must be taken and a brief sexual history should elicit whether the patient is having intercourse or is planning to start a sexual relationship. The physician should estimate the degree of risk and if contraception is needed, the patient's level of intellectual function.

Methods of Contraception

Periodic abstinence

The patient must be able to determine her periods of relative infertility by detecting subtle changes in cervical mucus or by maintaining immaculate records of menstruation. This may render these methods unsuitable for the intellectually handicapped patient.

Barrier methods and spermicides

When condoms and diaphragms are used with spermicides they provide effective contraception. The failure rate is reported to be as low as 2/100 woman years.[28]

These methods can be used by intellectually impaired people. If both

partners make the decision to use this type of birth control, the more capable can assist the more disabled.

Oral contraception

The combined oral contraceptive pill is useful for the retarded patient. The medication demands regular administration and this may have to be supervised by a partner, parent or other individual who provides social support. The physician must carefully assess the possibility of adverse drug interactions with other medications, especially if the patient is taking antiepileptics, antidepressants or tranquillizers.[29, 30]

Since many retarded adolescents are accustomed to taking daily medication, the addition of an oral contraceptive may cause no difficulty. Preparations supplied in packages of 28 tablets make taking a pill each day a habit.

Some patients will experience a reduced cycle length, regular menses and reduced menstrual flow. However, care must be taken to protect the patient from break-through bleeding. The retarded adolescent tends to tolerate irregular vaginal bleeding poorly.[31] Bleeding which occurs early in the cycle, before the tenth pill is taken, or never ceases completely after menstruation, is due to insufficient estrogen activity. Bleeding in the latter half of the cycle is due to insufficient endometrial activity. After pathological conditions have been excluded, the choice of pill should be changed to meet the patient's needs.

Side effects, of course, are as likely to occur in handicapped people as in the general population. Counselling about them is essential for compliance.

Intrauterine Devices

The use of an intrauterine device by a mentally retarded person or a minor raises several ethical issues. Although birth control is much less invasive than surgical sterilization, it does pose definite health risks. Birth control should be provided only when valid consent has been obtained. The IUD may be satisfactory in a well-motivated, consenting patient; the device might also appeal to a paternalistic physician or concerned parent. Inserting such a device, however, may cause an intellectually impaired patient great anguish. She may be terrified of a pelvic examination; she may find the act of having something inserted into her vagina repulsive; she may suffer continual cramping, abdominal pain and irregular vaginal bleeding.

Before prescribing an IUD, it is necessary to discover any medical condition which might contraindicate its use. Caparulo and Kempton[3] suggest that the patient should be shown the IUD, allowed to handle it and, perhaps, insert it into a model uterus. She should be told why she must search for and identify the string periodically, and shown how a physician would remove the device.

Physicians should use audiovisual aids as much as possible when they discuss birth control. This will help the patient understand what is happening to her and enable her to give informed consent.

Sterilization

In 1979, the Law Reform Commission of Canada published a working paper entitled "Sterilization—Implications for Mentally Retarded and Mentally Ill Persons".[32] This impressive document discusses all aspects of non-consensual sterilization, and includes a detailed examination of the social, biomedical and moral arguments. It is required reading for anyone who wishes to pursue this topic.

The question of sterilization culminates parents' struggle to deal with anxieties about their mentally handicapped child's sexuality. One mother said: "I see no unreasonableness in making careful, thoughtful decisions for a mentally handicapped person with regard to his or her possible parenthood by seeking out sterilization";[9] another mother felt that "In all circumstances the less dramatic, less restrictive alternatives (to sterilization) should be tried first and given a damn good try"![33] Despite these contrasting views, Wolf and Zarfas found most parents agree with sterilization and do not think a third person or group should legally intervene when they and their physician decide on sterilization for their children.[8]

Surgical sterilization

Both tubal ligation and vasectomy have become increasingly popular methods of permanent contraception.[35, 36] In 1973, *Good Housekeeping* magazine reported that voluntary sterilization had become the favorite form of contraception among married women aged 30-34 and second only to the pill among women of all ages.[37]

Despite early reports of a possible relationship between vasectomy and arteriosclerosis,[38, 39] subsequent studies have identified no clinical consequences of vasectomy[40] and it remains popular. Should the mentally retarded not have free access to these procedures that are readily available to the non-handicapped? Should sterilization not be available on a 'voluntary' basis?

Voluntary sterilization

Voluntary surgical contraception has been promoted for the mentally handicapped.[41] However, this approach raises several serious questions. "On the one hand, is it fair to deny to retarded individuals a method of birth control which has become so popular among the rest of the community? On the other hand, to what extent can we allow sterilization of individuals who are generally under the control of others and whose competence to protect themselves is doubtful if we are opposed to sterilization which is other than truly voluntary"?[35] How 'voluntary' is voluntary sterilization? Baron cites the 1968 case of a 35-year-old woman with an IQ of 71 who was given the opportunity to leave a Nebraska institution if she agreed to be sterilized. The court argued: "The order does not require her sterilization. It does provide, . . . that she shall not be released unless she is sterilized. The choice is hers". Is this truly voluntary sterilization? Coercion may lead a mentally handicapped person to seek 'voluntary' sterilization.

Family physicians encounter several problems when handicapped adolescents or adults request 'voluntary' sterilization. Physicians must satisfy themselves that the patient truly understands the nature, consequences and implications of the proposed sterilization. This may be a time consuming and difficult task but it is mandatory. The doctor must

1. fully explain the procedure.
2. explain its purpose.
3. clearly describe what will occur.
4. describe the operation's benefits.
5. describe the operation's permanence.
6. describe risks, their seriousness and the probability of them occurring.
7. disclose alternatives and their relative risks and benefits.

8. answer any and all questions.
9. determine if the person is going through the procedure voluntarily.
10. tell patients that they are free to withdraw consent and assure them that no punitive action will result if they refuse treatment.[42]
11. inform patients of any need for post-treatment supervision.
12. determine whether all legal obligations have been met.[3]

Then, and only then, can we give "full protection to the rights and interests of those who are mentally retarded without depriving them of the options for contraception available to the rest of the community".[43]

Involuntary sterilization

Most retarded people can understand the implications of sterilization.[21] Sterilizing mentally handicapped people against their will can produce serious and significant psychological damage[44] and should never be condoned.

Arguments for compulsory sterilization of the mentally handicapped are that it benefits society and the state, the handicapped themselves, and their potential children.[32]

The argument that eugenic sterilization benefits society has a long and undistinguished history. In the United States, the first law permitting involuntary sterilization was passed in Indiana in 1907.[45] In Canada, "no service was done to the science by the use of the name 'eugenics boards' to describe the statutory boards in Alberta and British Columbia dealing with mental patients feared likely to transmit to their progeny characteristics harmful to society; the recent demise of these boards leaves behind a disquieting record of compulsory sterilization upon highly suspect scientific grounds".[46] Although the eugenic argument for sterilization is the weakest of all,[47] some people still advocate sterilizing mentally handicapped people for poorly disguised eugenic reasons.[48-51]

The second argument in favor of non-consensual sterilization states that it is beneficial to the handicapped themselves. Sound therapeutic reasons may justify sterilization. These include conditions such as severe cardiac or kidney disease and obstetric problems which mitigate against further pregnancies, such as multiple cesarian sections.

Others have argued that the mentally handicapped are unable to raise children.[52, 53] These arguments come precipitously close to those advanced by proponents of eugenic sterilization.

Other arguments include handicapped people's inability to handle the financial burden of parenthood, especially if they live on welfare or work at low-paid jobs. To single out this group from other disadvantaged citizens is unconscionable.

Other arguments advocating non-consensual sterilization are related to personal hygiene; this argument will be discussed further under "Hysterectomy".

Third party consent

Recent legal decisions have done little to answer the question of paramount importance to physicians: "Is sterilization (or for that matter, any non-therapeutic operation) ever lawful when performed upon a minor or upon an adult whose consent may be invalid because of mental illness"?[48] Family physicians must ask themselves how legitimate third party consent is—even when the third party is a competent, caring and concerned parent. While parents may feel they have the right to decide about issues such as sterilization,[8] Bayles noted that, "the interest of parents and mentally incompetent children may diverge. Parents may fear that if their child begets offspring, they would ultimately have the primary burden of raising them. Moreover, sterilization of the mentally incompetent child may make her care easier, since there would be fewer problems concerning sexual activity or contraception".[53] The problem is magnified when the person responsible for third party consent has other conflicts of interest.[33, 54]

The American Association on Mental Deficiency's position paper, "Rights of Mentally Retarded Persons", states that the mentally handicapped have a right "to have a responsible, impartial guardian or advocate appointed by the society to protect and effect the exercise and enjoyment of these foregoing rights, insofar as this guardian, in accordance with responsible professional opinion, determines that the retarded citizen is able to enjoy and exercise these rights".[55] The key words are "impartial" and "protect". When the family physician faces a request for sterilization involving third party consent, he must inquire about the impartiality of those giving consent and decide whether they are motivated by a desire to protect the patient's rights.

The CMPA's position

In 1980, Kenneth G. Evans, counsel for the Canadian Medical Protective Association, outlined the CMPA's position on sterilizing the mentally retarded.[56] To our knowledge, the CMPA's position has not altered substantively since that time.

Mr. Evans states: "When, after giving very clear consideration to the circumstances of the specific request (for sterilization), the doctor concludes that the proposed sterilization can be justified only on non-medical grounds, as a contraceptive measure or for the convenience of the parent or guardian, he must refuse the request". He also comments that "In Ontario and probably in all provinces, a doctor should refuse to perform a sterilization procedure on a mentally retarded child under the age of 16 unless the operation is medically necessary for the protection of the physical health of the child".

When proposed surgery might be viewed as therapeutic, the CMPA advises that "any decision to proceed or not is a matter solely within his (the physician's) clinical judgment". However, "any decision to proceed with the sterilization procedure, even in these instances, does not provide the doctor with any absolute assurance as to his medical legal position".

The Association concludes that "until the current debate and legal controversy about sterilization procedures on minors and the mentally retarded is resolved, doctors would be well advised to exercise caution and to seek advice before proceeding with any such operation".[56]

Hysterectomy

Some authors advocate hysterectomy for sterilization and hygienic purposes.[57, 58] Wheeless, a staunch advocate of abdominal hysterectomy, states, "Abdominal hysterectomy is the preferred technique for surgical sterilization in the mentally retarded for the predominant reason that it eliminates the menstrual period, eliminates the most common cause of gynecological pathology, and is a 100% effec-

tive method of female sterilization".[59]

We cannot support such a position. We agree with Milligen that "The only time that one considers a hysterectomy for sterilization is if there are other factors relating to the uterus and to its functions which indicate that the morbidity of leaving the uterus in is potentially greater than the morbidity of taking the uterus out. . . . In medicine, with the risk of greater morbidity, one never does more than necessary unless there is some indication to do so".[34]

Other authors suggest that if a woman requires much assistance to manage her own menses, she is also likely to need help with urinary and rectal control—problems which are much more troublesome in terms of personal hygiene.[60] We agree with the Law Reform Commission that "the beneficial nature of the hysterectomy solely for hygienic purposes is therefore put into question".[32] The use of hysterectomy to sterilize and control menses suggests that the mentally handicapped do not merit the dignity and rights of the non-handicapped.

Conclusion

Rioux provides some important guidelines to help family physicians deal with the vexatious problem of sterilization.

1. The physician should presume that the mentally retarded have the same rights as all other people.
2. Mentally handicapped patients should not be assumed incapable of consent, even if they are institutionalized or subject to a court order.
3. Mentally handicapped people, especially minors and those who are institutionalized, may not have the same freedom of choice as other people.
4. The physician should insure that the patient understands the procedure and has fully consented without undue influence.[61]

Prescribing contraception and sterilization is a very difficult problem for the family physician. On the one hand, he is anxious to help parents to 'do what they think best' for their handicapped son or daughter. On the other hand, he must always protect the handicapped person's rights and autonomy, especially when difficult issues of consent, surgical sterilization and hysterectomy are involved.

When asked what she wished doctors had told her about her mentally handicapped son, a mother responded: "that my child is a child, as any other. That while his needs are greater than most, he should be treated as any normal child is, with love and affection and respect for his humanity . . . That he is, more than anything else, a person".[62] All family physicians facing a request to sterilize a mentally handicapped person should remember this mother's plea; involuntary sterilization and hysterectomy have no place in the management of persons. ◉

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